

**BUILDING BLOCKS® Early Intervention Service**  
**Parent Information Sheet**

**Parent & Family Well-Being**

---

Caring for a child with exceptional needs and accessing intervention, while balancing the requirements of the rest of the family can be both a rewarding and a demanding task. Dealing with the initial diagnosis is often a time of great stress for both parents and their extended families.

Parents of children with exceptional needs often experience a wide range of emotions, each with a different intensity. It is important to remember that everyone adapts in his or her own way. One person may express their feelings very openly, another may suppress their feelings by immersing themselves in their work. Some parents report feeling numb for several months, others report feeling fearful as to what the child's future may hold. All these responses are very normal reactions to a stressful situation.

Many parents find it helpful during this time is to seek out someone, perhaps a close relative or friend, who will listen and understand. Similarly, talking to other parents who are going through the same experience is also often beneficial. Many parents of children with autism report that reaching a stage of “acceptance” regarding their child's disability was a gradual process resembling a journey, which had many ups and downs.

Although there are resources and professionals available to assist families during this difficult time, no one can tell you how to feel or when you should expect to feel differently. What can be provided however, are some suggestions for managing these emotions in a way, which may assist you in coping better.

## **General Suggestions to Assist Families to Cope Better**

### **Taking some Time for Yourself**

All the additional jobs you do for your child with a disability mean that you have extra responsibilities. In many instances, the primary caregiver often spends most of the day giving to everyone else, leaving no time for him or herself. It is important however, to plan and ensure you get some time to yourself in order to “re-charge your batteries”. Ask people around you for help and respond to any offers of child-minding from friends and family members, even just for short periods of time, in order to lighten your load. You will find, that with a little guidance, other people are able to look after your child and ensure their needs are met while you take a break.

Childcare can be accessed through: Occasional Care Centres, Family Day Care, Long Day Care Centres, Pre-schools and Respite services. Contact your local Council for a list of childcare options in your area. Assistance with housework can also be accessed at reduced costs through agencies like “Home Care” and “Dial an Angel”.

### **Staying Healthy**

In addition to taking time off to stop and relax it is important to make sure that you get enough sleep, a balanced diet and regular exercise. If you aren't physically healthy it becomes even more difficult to take care of your family. Rely on resources which you usually draw on during traumatic situations.

### **Sharing Your Emotions with Others**

Talking about your feelings with friends and family members can help to share your load. Allow these feelings to surface, because without some release, you may be unable to think clearly at a time when you need all the energy you can gather.

Counselling can be helpful to discuss and cope with the emotions you may be experiencing. Your local Community Health service will have free counsellors you can visit or your GP can refer you to other counselling services. There should be no criticism about the emotions you are experiencing.

## **Supporting each other**

Parenting a child with autism can both strengthen and challenge the relationship between you and your partner. Often, the need to solve difficult problems together can bring couples closer, however, even the strongest of relationships can be weakened by the stress of raising a child with additional needs.

Remember, your partner may be responding differently to you in regards to the diagnosis. One of you may be more emotional, the other less communicative. One may find comfort in searching for as much information about autism as they can, the other may find the same information overwhelming. It is important, therefore, to talk about how you are both feeling and what you can do to help each other during this difficult period.

Although it can be difficult to organise, couples often find that taking breaks without their children helps renew their energy. Give yourselves permission to relax and enjoy each other's company.

Try to make important decisions about your child together. Often, the parent who is involved in all the physical "running around" to therapy feels better equipped to make decisions about what is the best intervention for their child. By sharing information equally and having both partners involved (even if not always physically), these decisions can be made together and relieve some of the stress for the more involved parent and reduce the isolation often felt by the other.

For single parents, there are additional challenges. Accessing support services and child care, in order to have some time for yourself can be helpful. Accessing friends and extended family for assistance can be beneficial and provide an important source of support.

## **Supporting one Another as a Family**

Talking openly about your feelings, hopes and fears with family members, can reduce some of the burden on the major care giver. Your partner, other relatives and other children may cope better understanding and sharing with you your good and bad days. Often siblings may have their own ideas about their sibling's disability, its' cause and what the future may hold for that child and themselves. It is important therefore to give them good quality information, which is appropriate for their age. Your other children may also benefit from 1:1 attention and will need to have

opportunities to express themselves and participate in solving problems as part of the family. See also the BUILDING BLOCKS® Information Sheet on Issues Related to Siblings for more information.

### **Accessing Quality Information**

Learn what you can about Autism. Facts often replace worry and inaction, however it is important to read small amounts of relevant information so you do not become overwhelmed. With the enormous amounts of information currently available to families via the Internet, it is vital that you try and access current and reliable information from reputable sources. Remember, everyone's child is different and not everything you read will apply to your own child. Take time to observe your child, his/her likes & dislikes, learning style etc. Learning about how your own child learns best will help you make more informed decisions about intervention options.

### **Taking Note of Progress.**

Keeping a journal of your child's daily experiences can help you notice the little gains your child is making. Take note of small gains and achievements your child makes and remember that over time, real progress is being made. It is important to maintain hope by celebrating the individual signs of growth and change that you see.

### **Meeting Other Parents of Children with Autism**

Meeting and sharing your feelings and experiences with other people in similar situations can be a great support. Other parents of children with autism may be able to share strategies and ideas that have worked for them as well as really understanding where you are coming from. Contact details for established Autism Support Groups in different areas of New South Wales are available by contacting the Autism Information Line on 02 8977 8377. In addition, the **"Someone to turn to..."** program matches families of newly diagnosed children with "veteran" parents of older children with autism. Contact the Autism Spectrum Australia on 8977 8300 for more details.

### **Taking action.**

Many parents gain strength working with others on behalf of all children with autism. Lobbying and advocating for additional resources, community programs, or school services can help parents see themselves as important contributors to the well being of others as well as their own child. One organisation which is active in lobbying at a national level is "A4 Autism, Aspergers Advocacy" their web address is: [www.a4.org.au](http://www.a4.org.au).

### **References:**

Autism Society of America website, *Stress on Families Fact Sheet*, <http://www.autism-society.org/PageServer?pagename=livingfamily>

The Spastic Centre of New South Wales website, (1998). *Tips for Looking After Yourself Fact Sheet*, Section 3- Fact Sheet 16

Singer, G. H. S., and Powers, L. E. (1993). *Active coping skills and strategies for family interventions*, Maryland: Paul H Brookes Publishing.